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ABSTRACT

This digest provides a demographic profile of family caregivers and discusses the emotional and physical burdens on family caregivers. It examines how caregivers cope with these burdens and highlights research findings on the most effective coping strategies. The digest concludes by summarizing the challenges to the helping profession in addressing the needs of family caregivers. (TE)

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# Family Caregiving

*Nancy Beekman*

## Demographics and Aging Trends

In the past 20 years, the older population in America has grown twice as quickly as all other age groups. Just as the population in general is aging, the older population itself is aging. The 85 and older age group is expected to be seven times its present size by the year 2050 (U.S. Select Committee on Aging, 1988). This population trend, which could result in a large number of frail elderly people in need of caregiving services, is accompanied by several other trends which suggest that caregiving may become more difficult to provide in the future.

The most commonly cited of these trends are an increase in life expectancy, a decrease in the birth rate, and an increase in the participation of women in the labor force (Montgomery & Borgatta, 1989; Pratt & Kethley, 1988; Wisendale & Allison, 1988). The increased life expectancy may result in caregivers themselves being older adults. Individuals in their sixties or seventies may find themselves being the primary caregivers for parents or other relatives in their eighties and nineties. The increase in childlessness and the trend toward having fewer children will result in fewer adult children to care for a greater number of older adults in the future. The trend toward more women being employed leaves these traditional caregivers little time to care for an elderly relative in addition to other responsibilities. The increased divorce rate and the geographic mobility and dispersion of families will also make it difficult for families to provide the care needed by the elderly.

In spite of available formal services, informal caregivers continue to provide the majority of long-term care to older adults and family care is recognized as a critical factor in preventing or delaying nursing home placement (U.S. Select Committee on Aging, 1988). It is estimated that 80% of care for older adults is provided by their families (Pilisuk & Parks, 1988).

## Caregiver Profile

Although anyone can become a caregiver, caregivers tend to be women who are approximately 57 years old (U.S. Select Committee on Aging, 1988). Adult children caring for a parent tend to be between 40 and 59 years old. Most are married women with families of their own. An estimated 44% of caregiving daughters and 55% of caregiving sons are employed (Blieszner & Alley, 1990). These statistics suggest that many adult children caring for their parents have family and work obligations that may conflict with caregiving responsibilities. Caregiving spouses tend to be in their late 60s and 70s. When compared to the general population, caregivers are less likely to be employed and more likely to be poor or near poor and in fair to poor health (U.S. Select Committee on Aging, 1988). The majority of caregivers have been providing care for 1–4 years; 80% of family caregivers provide unpaid assistance seven days a week and primary caregivers report spending between four and six hours a day in caregiving duties (Pilisuk & Parks, 1988; Stone, Cafferata & Sangl, 1987).

## Caregiver Burden

Distinctions are often made between objective and subjective caregiver burden (Montgomery, Gonyea & Hooyman, 1985) or between caregiver burden and stress (Pilisuk & Parks, 1988), with objective burden referring to management of tasks to be performed and subjective burden or stress referring to the appraisal of the strain on the caregiver. Both burden and stress must be examined to assess the effects of caregiving on the caregiver.

Caregiving is a time-consuming responsibility which inflicts various limitations on the caregiver's personal life. Confinement has been cited as the most stressful infringement on the caregiver's lifestyle (Bliesner & Alley, 1990; Montgomery, Gonyea & Hooyman, 1985). Restriction of one's social life is the most frequently cited problem among caregivers of moderately and severely impaired persons (U.S. Select Committee on Aging, 1988). Role conflict resulting from the competing demands of the care recipient, other family obligations, and employment responsibilities is often a major complaint of caregivers.

In addition to competing roles, many caregivers must adjust to a new role. Becoming a caregiver results in a change in the former relationship between the caregiver and the care recipient (Blieszner & Alley, 1990).

Seventy-seven percent of employed women who also provide care reported experiencing a conflict between work and caregiving demands, and 35% believed that being a caregiver adversely affected their work (Bureau of National Affairs, Inc., 1988).

The emotional and physical demands of the care recipient can also cause stress among caregivers. Caregivers experience more stress if the care recipient's impairment results in disruptive behavior and improper social functioning (Blieszner & Alley, 1990). Several studies have shown that the degree of caregiver stress increases as the care recipient's level of functional impairment becomes more severe (U.S. Select Committee on Aging, 1988).

Many caregivers experience problems with the physical demands of caregiving. Some report difficulty in lifting or moving their care recipient, others report difficulty in performing personal care tasks. Barusch's study (1988) of elderly spouse caregivers found that the most prevalent problems experienced by caregivers involved the cognitive aspects of caregiving. Caregiving spouses reported grief over the loss of the spouse they once knew. Seventy-six percent reported worrying about their own health and what would happen if they became ill. Many expressed some form of generalized anxiety about the future. Sixty-seven percent reported feeling depressed.

Many caregivers report family conflict and the loss of friends and activities as a result of caregiving. The emotional and physical strains of caregiving often lead to deterioration in the caregiver's own health. Although caregivers report physical, financial, and family strains associated with caregiving, the most negative consequences of caregiving on caregivers seem to be the emotional strain of caregiver burdens.

## How Caregivers Cope

The most common coping response of the caregiving spouses studied by Barusch (1988) was to seek help when they had problems, especially in the areas of care management and health problems. The second most common coping response was to simply not cope. Spouses reported not coping with sexual problems, guilt feelings, feeling their spouse was overly dependent, arguments with their spouse, excessive demands made by others, worries about future financial problems, managing money, and worries about their own health. Another study found that 12% of caregivers drank alcohol to cope with the psychological strains of caregiving (Bureau of National Affairs, Inc., 1988).

## Effective Coping Strategies

Interventions designed to help caregivers cope with caregiver burden and stress have focused on individual coping strategies, respite services, and support groups and other group interventions. Results from studies evaluating the effectiveness of different interventions have been equivocal.

**Individual Coping Strategies.** Caregivers themselves report having the most success when they could somehow change a stressful situation and reported highest levels of satisfaction when they could change it alone (Barusch, 1988).

**Respite Care.** Compared with caregivers receiving no respite care, caregivers of Alzheimer's patients who had formal respite care were able to keep their relatives out of institutions for a longer time (Lawton, Brody & Saperstein, 1989). Participants reported high levels of satisfaction with respite services, yet respite neither alleviated caregiver burden nor promoted caregiver mental health significantly. A program which provided adult day care services to older adults with dementia did report a reduction of caregiver burden (Eddowes, 1989).

**Group Interventions.** One study of a group intervention for family caregivers of dementia patients showed that, at post-treatment, caregivers who received the intervention showed no greater change in caregiver depression, life satisfaction, coping, or social activity than did caregivers on a waiting list who received no intervention (Haley, 1989).

In one study, individuals caring for impaired elderly relatives were assigned to either a waiting-list control group or to one of five treatment groups that received different combinations of services, including seminars for caregivers, support groups, family consultation services, and respite care. One interesting finding from this study was the reluctance of participants to use services. In spite of free access to services and encouragement to use services, almost one-third of caregivers did not use services (Montgomery & Borgatta, 1989).

## Challenges to Helping Caregivers

The reluctance of family caregivers to use services for which they are eligible and the preference of caregivers to solve problems on their own present challenges to those trying to provide services to family caregivers. Caregivers who have little time to meet their family, work, and caregiving responsibilities often feel they do not have any time left for support groups or other interventions. Simply locating family caregivers in need of support and getting them to accept such support may prove difficult. Many family caregivers do not seek outside help until they have reached a crisis point.

The literature has illustrated that a variety of coping skills are often needed by caregivers in order to deal with a variety of problems. Barusch (1988) recommends that training programs teach techniques for personal control in order to help caregivers cope without outside help, but also provide information about community resources and discuss caregiver feelings about seeking and accepting help in an effort to prepare the caregivers for a time when they may be unable to cope alone.

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